

Preparing Families for Their Child's Hearing Screening

Steve Shuman: Welcome, everybody. I'm Steve Shuman from the National Center on Health Behavioral, Health, and Safety. Today, we're seeing Preparing Families for Their Child's Hearing Screening. It's my pleasure to introduce the National Center's subject matter expert on hearing screening, Dr. Alejandra Ullauri. Alejandra?

Dr. Alejandra Ullauri: Thank you, Steve, and hello, everybody. Thank you for joining us. Welcome to this session. Today, we're going to be talking about preparing families for their child's hearing screening. I have to warn you – this is one of my favorite topics.

My name is Alejandra Ullauri. I'm a bilingual audiologist. I'm certified by the American Board of Audiology in cochlear implants, and I've been working with children with hearing loss for about 20 years. I'm very excited to be with you today.

In today's agenda, we're going to be talking about why hearing screenings are important, what information is important for us to share with the families we work with about hearing screenings, how to do that in an effective way, and where to find resources for our families. Let's start with question No. 1: Why are hearing screenings important? First of all, an undiagnosed hearing loss can have long lasting negative effects on a child's language development, behavior, social interaction, and education.

I just want to bring up some statistics for you. Between one and three of every 1,000 babies born are born with a hearing loss. Actually, hearing loss is the most common birth defect in the U.S., and those numbers will double by the time a child enters the school system so hearing loss is more common than what we think. Providing hearing screenings during early language learning years is critical for helping children receive the benefits of early identification and intervention.

The good news is that Head Start programs and Early Head Start programs provide hearing screenings during their hours, whether it's in their centers, doing home visits, or by partnering with community centers. These are great news for our parents and families because they don't have to take time off from work to take children to receive a hearing screening. Head Start programs provide them on site or during home visits or partnering with community services with community centers. To recap, hearing plays an essential role in a child's speech and language development, social and emotional well-being, as well as school readiness and success.

For many of us here that are familiar with the screening with what hearing screening programs are ... First of all, a hearing screening is a tool that helps us identify children who need further testing to confirm or rule out a hearing loss. A hearing screening is not a diagnostic test, and a hearing screening must lead to diagnosis and management for those identified with a hearing loss. Hearing screenings are only the entry point, only the first step.

They have to lead to diagnosis so we can complete a diagnosis of those children who have been identified with a hearing loss, and then for those diagnosed, we can help them access the treatment and management services they need.

What kind of information about hearing screening programs is important for our families to know? I figure, in order to keep the message clear for families, maybe it's easier if we divide families in different groups depending on where they are in the hearing screening process.

I was thinking about our first group is the families ... In group No. 1, we have those families that are new to the hearing screening process. Their children are about to be screened for the first time. In group two, we have those families that have undergone – that underwent the first screening. Their children did not pass. They were rescreened – still did not pass – and now they are being referred to their primary health care provider.

And then we have group three that are those families that their children were screened, rescreened – they still did not pass. They went to see a health care provider, came back, they were rescreened – still did not pass. Now, those families are going to be referred to a pediatric audiologist for diagnostic services.

I'm thinking of putting families in these three different groups so we can tailor the information we're going to share with them, depending on where they are in the screening process. For those families in the first group, remember, these families are new to the screening process. Their children are just about to be screened.

For them, it's very important to know that, first, unknown hearing losses can have a negative impact on a child's development and learning. It's very important that we conduct hearing screenings because we cannot tell if a child has a hearing loss just by looking at them or just by playing with them or just by interacting with the child. And No. 3, it's very important that families understand that some hearing losses are temporary, but some are permanent, and either way, children need services. Children that have either a temporary hearing loss or a permanent hearing loss, they still need access to the help they need. So very, very important for parents, for families to understand this.

They also need to know that hearing screenings are quick and painless. They give us information about a child's likelihood to hear well. They're not diagnostic tests, and if a child does not pass the screening, we will rescreen them again in two weeks. For those families that are in group two, those families are those that are being referred to a primary health care provider. It's important for these families to know that when a child does not pass the hearing screening, it could be for two common issues.

One is earwax buildup, and two, it could be ear infections, which are very common in early childhood. No. 2, families need to know that the child will go and see a primary health care provider. They will get their ears cleaned or treated, depending on what's going on. Then, after that appointment, they will come back, and we will repeat this screening.

Doing this will ensure that the child's hearing health is checked without any delays. These three messages are very important to share with families that are in the process of being referred to see a primary health care provider. In group three, we have those families that came back from the primary health care provider, their ears were cleaned, or their ears were treated for an ear infection, and now, we repeated the hearing screening and the child still did not pass the screening.

Now, these families and their children are going to be referred to a pediatric audiologist. For families in this group, it's very important to understand that a hearing screening is not a diagnostic test. It is only a tool to identify those children that need further testing. Also, a diagnostic hearing test that will be performed by the pediatric audiologist will help us confirm or rule out a hearing loss.

Knowing this information will help the child access the services they need in order to continue to develop language and continue to learn. Here is just a quick reminder of how the screening follow up protocol works. You can access this information in the Echo Initiative website. We're going to share with you lots of resources at the end of this presentation that you can download for your review.

When we're thinking about referring families to an outside health care provider or a pediatric audiologist, I want to introduce you all to the "Ask me three questions." This is a great tool that we can share with families. It was created by the Institute for Healthcare Improvement in Massachusetts, and the idea behind this tool is to help families ask questions that will lead to better understanding of their conditions and also a better understanding of the recommendations given.

You can download information about the "Ask me three questions" in their website. We're going to share the information with you in a resource document at the end of this presentation, but I also want to let you know that the information ... You can download brochures and posters to use with families in English and Spanish. Just remember that effective communication encourages families to take an active role in managing their child's overall health.

Let's talk a little bit about how we're going to share this information. We know why hearing screenings are important. We know what kind of information about hearing screenings we need to share with families, and we know what kind of information families will need depending on where they are in the hearing screening process.

Now, let's talk about how we are going to share this information. We want to make sure that the information we share, it's received by the family. We want to share this information in an effective manner. Three things that we need to consider when we are sharing information with families. We need to consider health literacy, cultural and linguistic backgrounds, and we need to consider health equity.

Let's just go in more depth into each one of these. Health literacy. It's one's capacity to obtain, process, and understand basic health information needed to make appropriate health decisions. There is a great tool in the ECLKC website that is called "Tips for Families." We encourage you to review that document. Great suggestions that you can use with your families to prepare them when they attend health care and medical appointments.

When we talk about cultural and linguistic responsiveness, this refers to practices that support the learning, development, and engagement of children from diverse linguistic backgrounds. It also applies to how we engage and interact with families.

We have two great resources, again, in the ECLKC website. We're going to share all the links with you at the end, but I want to pause here and just make sure that everybody understands that, when families communicate with health care providers in their own language, they're more likely to ask questions. They are more likely to understand more their condition, and hopefully, they are more likely to follow the recommendations.

As you build your referral network when you find health care providers or on pediatric audiologists where you're going to refer your families, it's very important to take in consideration adding providers that speak the language that your families also speak. Even though that might not be always-- even though you might not always find those providers, if you cannot find a provider that speaks the same language as the family, the next step would be to find a center that will provide the family with professional interpreters.

Very, very important for all of us to know that health care organizations that receive federal funding must provide interpreting services to their patients. Interpreting services can be provided in person and also can be provided in a remote manner. Whatever it is, just know that if you cannot find a provider that speaks the same language as the family, you can find a health care center that will provide professional interpreter. Very important the word professional interpreting, because families need to receive the information from their health care provider in an accurate way, so very important that these services are provided by professional interpreters.

Another thing to remember is that just to facilitate the health care encounter for these families, it's a good tip for you to remind them or if you are the one making the appointment that a professional interpreter is requested at the time you make the appointment. That way the health care provider, the health care center can prepare to have those services available to the family on the day of the appointment.

If the appointment is made and nobody mentions interpreting services needed, then on the day of the appointment, some centers might be able to accommodate for that. Some other centers might ask the family to reschedule the appointment because they need to book a professional interpreter to be on site. It's a lot easier if the information like that is brought up when the appointment is made. Just for us to remember is that language, sharing this same language between family and health care providers is a big, big plus for our families to understand their condition, ask questions, and hopefully understand and follow the recommendations.

We also want to talk about health equity, and health equity is the principle underlying a commitment that we all have to reduce and ultimately eliminate disparities in health care and its determinants, including social determinants. Basically, it means everything that we do to ensure that everybody has access to health care services, and when we think about health equity and we think about families accessing services, the goal is to get them to receive the services they need. We also need to pause and think, what kind of barriers families might face when they try to access the health care system, and there are many barriers.

Some of them might not be very clear to us. Some families might struggle accessing services even though we've recommended that they see a health care professional because the child did not pass the screening or maybe now we're recommending that the child sees a pediatric audiologist. For some families, they struggle accessing the health care system because they've experienced discrimination or racism in that same system before.

Those are things that might not be clear to us but that we need to dig further, understand why the family is reluctant to access these services, and help them navigate those barriers so they can act. The main goal, as I said, is for these families and their children to access the services they need. Very important that ... Because all the topics that we are talking about in this slide might not be very clear. It might not be crystal clear to us when we meet the family. Very important that we are aware about this and that we can dig further, ask more questions, and help families navigate the system so they can access the services they need.

Possible red flags of low health literacy. A family that may come to see you and they ask no questions, they make excuses for not reading information provided. Maybe they say, "I forgot my glasses." They seem a little quiet, passive. Some might actually come across as angry, demanding, and they're maybe not completing registration forms.

In those situations, those might be red flags the family actually has some low health literacy. There are great resources that we can learn from, and we put a link there on family engagement and cultural perspectives. Please visit that site. I also wanted to bring this up. This is a great resource that it's called the "Brief Health Literacy Screen," and the original document has four questions.

There is a new document that has been adapted for hearing health care use, and this document has three questions. Very easy to use. It might help you identify families that are struggling with health literacy so you can have them access information, understand information. You might want to adapt the information you share with them, and so on.

In the adapted version, you will ask the family, "How confident are you feeling out medical forms by yourself?" The answer might be not at all, a little bit, somewhat, quite a bit, or extremely, depending on the answer they get a score. One point for not at all. Five points for extremely.

The next question is, how often do you have someone help you read hospital materials? No. 1 always, No. 2 often, No. 3 sometimes, No. 4 occasionally, No. 5 never. The maximum score is 15 points. If somebody scores 9 or less, that reflects inadequate health literacy.

If you feel health literacy could be something that it's not clear to you. You've seen red flags when you interact with the family, they had difficulties filling up the forms, they're not asking questions. Those red flags can be easily ... You can have a more objective way to address health literacy if you use a little questionnaire, a short questionnaire like this one.

It could be a great tool to help you identify families that need more help when it comes to dealing with the information. When we share information, there are some recommendations. One is to use plain language and avoid medical jargon. Break down information into small concrete steps. You can concentrate on three key points and messages per visit.

I love these because sometimes in an effort to help families understand their condition, we overload them with information. If we concentrate on three key points and messages, we can help them build understanding. We can also use a teach back method to assess comprehension.

If we use printed information as an education tool, we can ensure that that's written at or below fifth grade reading level. Also, you can use visual aids, graphs, or pictures when presenting new numerical information. Again, we have two great links here that we will share with you with more information about this topic. If you have not visited the plainlanguage.gov website, I invite you to do so. Great information. These tips come from there.

They say, when you're sharing information, use you and other pronouns to speak to the reader. Instead of saying, "One might want to go to the doctor," you can say, "You want to go to the doctor to discuss blah, blah, blah." You also use "must" to express requirements instead of saying you may want to do something you can say you "must" do so and so.

Use active voice and simple present tense. Use short sections in short sentences. Use concrete, familiar words. Use lists and tables to simplify complex material and use base verbs instead of hidden verbs.

An example would be, "You need to make a payment on the company's website," instead of saying, "You must pay online." These recommendations are very important for all of us to keep in mind when we are choosing written information that we're going to share with families or when we are creating this information. If we are putting together maybe a letter, maybe a brochure ... If we are creating information or choosing information from somewhere else to share with families, keep these recommendations in mind.

The information you share is actually something that it's easy to understand, no matter who reads it. Sharing electronic information can be tempting but very important that we all keep in mind that, when we share electronic information, to access that information, families have to be confident in navigating the internet. They have to have digital literacy.

They must be able to access the internet. First of all, they have to have a computer. They must be able to navigate a computer, access patient portals, and comprehend the terminology and the text. Research has found that access to the internet and digital literacy can be a source of inequalities, especially for those from lower socioeconomic backgrounds, older adults, and for patients who do not speak English.

Again, as we discussed, we might share with families electronic information. There is nothing wrong with sharing this information. We just need to keep in mind that families not only need to be able to read and have health literacy, they also need to have digital literacy in order to access that information.

So far, we have discussed that we can share information in three different ways: in a verbal manner, written manner, and also we can share electronic information. If we share verbal information, we want to make sure we keep our languages plain, we break down information, we concentrate in three points.

And I want to remind you that, when we share verbal information, we have the opportunity to assess comprehension, so don't miss that opportunity because when we share written information or electronic information, families don't have to read it right there in front of you. They might put it in their handbag and take it home, and you don't know if they read it, and if they did read it, you don't know if they comprehend it, if they understood what they read. When we share with them information verbally face to face, that gives us a unique opportunity to assess if they are comprehending what we are sharing with them. Don't miss that opportunity.

If we share written information, same thing. Use plain language. It should be written below a fifth reading level. Use lots of visual aids, graphs to present numerical information and use pictures that represent the community you serve. If we share information in an electronic manner, make sure that those families have access to the internet, that they have digital literacy and they can navigate the internet, and share pages that contain information in their preferred language, but also information that is specific to their condition.

There is so much information in the internet – so much, so much that if we are going to share a page with them, make sure you give them the link to the specific information, that it's relevant to the family's case, and I'm going to give you a few examples. Before we get to the electronic information and how to make sure you're sharing relevant information, I want us to go over the "Ask me three questions." I want us to go over some examples as we were using this tool with our families.

Here is example No. 1. What is the main issue? This is a family that we are going to refer to a primary health care provider. If we practice the "Ask me three questions," what is the main problem? Your child did not pass the hearing screening.

What do I need to do? You must take your child to the primary health care provider. The health care provider will check your child's ears for earwax or possible ear infections. Why is it

important for me to do this? Because we need to ensure your child hears well for language development and learning.

Remember, the "Ask me three questions," it's very to the point. But also, the answers that we are reading right now are keeping in mind those plain language principles that we just learned. We're using "you," we're using "must," we're using present tense, active voice. Just make sure that all those tips, that you can include them when you prepare, information you're going to share with the family, whether you're going to have a discussion verbally with the family, whether you're going to mail a letter to the family, keep those in mind.

I love the "Ask me three questions" because it keeps it to the point. What is the problem, what do I need to do about it, and why is it important for me to do it? Here's another example. What is the main issue?

Your child did not pass the second hearing screening. What do I need to do? You must take your child to a pediatric audiologist. A pediatric audiologist will test your child's hearing to confirm or rule out a hearing loss. Why is it important for me to do this? Because your child has a hearing loss. They need to receive services so they can develop language and continue to learn.

I love this quote from an article from Palumbo. "Family engagement is reached when organizations engage, involve, enable, and activate families." The main goal is to get families to be active participants in their child's well-being, in their child's health care, and we want them to participate.

They are the main ... They play a major role in their child's access to services and in following recommendations and so on. I love for all of us to take a second, pause and just think about how we can involve our families, engage them, and activate them to participate. The next section is, where do we find all of these resources?

Where do we find resources to help our families or to share with our families? There is lots of information out there. I've chosen four major websites where you're always going to find great information. And within these websites, there is even more information of other links to other websites that have information on many different topics.

What I wanted to highlight here is that if you go to the CDC and you put hearing loss or deafness, there is so much information. It would be really, really, really hard for a parent or a family to navigate that information and to actually find the information that they need for their specific case.

These are great sites, and I would encourage you to visit this site and just see how long it takes you from getting to the CDC or getting to the NIH and then type in hearing loss and then get into the hearing loss website and then how many clicks it takes you to actually find your baby's hearing screening, site, information, document, and so on. It's very important that when we share information with families we've done the homework for them. We've visited these websites. We've actually chosen the specific links that we want to share with them and that

maybe we've downloaded already the documents. These are the documents that either we're going to share electronically, we're going to print, or these are the documents that we're going to discuss.

The main thing is that you really need to visit the websites and just realize how much information there is, how long it will take you to find the right information, and then do that homework for families because if we share with them so much that it's overwhelming, it's hard to navigate, it's easier if we help them build understanding and also that we have them access information that is relevant.

A child that is undergoing a hearing screening process, the family doesn't need to know about cochlear implantation in children with severe to profound deafness. Very, very important that we share relevant information with families and that we don't overwhelm them with sites. In these four websites, I think you will find great information. There is super useful and they're always updating their websites with new and evidence-based information.

I also encourage you to visit these websites often because things might change and so on, and you might find new, better information posted. Just as an example, I put together just these lists of resources, but what I wanted to highlight is that there are some resources for those families that are undergoing hearing screening and what they need to understand and what kind of information you need to share with them ... The Echo Initiative has great templates with scripts, forms, letters that you can use.

I will encourage you to review those letters with the lens that we just discussed from plainlanguage.gov. Very important that all the information you're getting ready to share with families and undergoes that lens, undergoes that review. Make sure that the information, it's properly written to share with ... It's written in a way that families will understand.

To give you another example, if a child has been diagnosed with a hearing loss, then we have great sites here about hearing tests or diagnostic hearing tests for children in the CDC. The child is being referred for diagnosis, we have information there. You can also find a pediatric audiologist at the American Academy of Audiology website. Then when children are diagnosed with the hearing loss and they are in need of hearing services, then we have other great sites with more information about early intervention, how to build language in children with hearing loss, and so on.

I guess the point I'm trying to share with you is that there is lots of information out there. If you tailor the information for your families, you share information with them that is relevant. Make sure to concentrate on three specific points to share specific links or maybe you're going to print out information. Make sure that it's written using plain language principles. I just wanted to give you an idea. All the information you can tailor for your families from all those great websites that we shared before, and we're going to share all these websites with you at the end.

Also, when you are building your referral network, here are some websites that you can visit. Keep in mind, when possible, find also providers that speak the language that many of your families speak. That's also something to keep in mind.

We shared a lot of information with you today. We're going to give you all the links to the different sites that we discussed, but if there are three things that I'd like you to remember from this presentation are keep information clear and simple with families. Stick to three main points when you share new information with them and encourage them to ask three questions from every health care provider they visit.

I love the "Ask me three questions," because it's not only relevant to hearing screening. It's relevant to health care, to accessing health care, so this is a great tool that they can learn from you, and they can transfer these to other appointments, not only to their hearing health care appointments. With that, we have some references and will be super happy to take some questions.

Steve: Wow. Thank you, Alejandra. That was, indeed, a lot of information. A number of the questions related to hearing screening tools and processes, and I just want to remind people that you did a webinar earlier in I believe April on how to do hearing screening. You did that in both English and Spanish, and that is already posted on the ECLKC, so we're not going to take those questions right now.

We just to remind people, you're also doing this webinar in Spanish. There were some questions about working with families for whom Spanish is their primary language, and this same webinar is being done in Spanish. But let's start with this question, because I think it's a good one, and I think it's a good one that ... It's not uncommon one that some programs may face: What are some good action steps to take if the family doesn't want to take their child to their primary care provider or audiologist, whether that they don't think it is important or they don't believe that the screening results are accurate, not so much if they don't have insurance or another barrier to access to care like transportation or child care for their other children? We're really talking about attitudes and knowledge here.

Alejandra: Thank you so much, Steve. That is a great question, and I want to go back to one of our slides at the very beginning of the presentation. What kind of information is important for families to know? I think this is one of my favorites, that we cannot tell if child has a hearing loss just by looking, playing, or interacting with them. A child could have normal hearing in some frequencies or pitch and have a significant hearing loss in some others. They will react to sound. They just don't access all the sounds that they need to hear in order to develop language and also for effective learning.

Very important that hearing loss is something that we cannot see. We cannot tell just it just by looking at a child. A mild hearing loss can be overlooked because a child can hear people talking directly to him, but he might not hear soft speech or somebody speaking at a distance. Things that are very important to do for learning. I love that point, No. 1.

No. 2 is that a child might have a hearing issue that can be easily solved by removing ear wax or by treating ear infections. Some hearing losses can be temporary; some can be permanent. But these children still need to access services. I think that highlighting those issues with families, it's very important.

The reason why we use hearing screenings here and screenings are not 100% accurate but they have high accuracy. This is why this is our preferred tool because we can use it with significant accuracy to find those children that need further testing. That's all it means.

If a child does not pass the screening, all it means is that we need to do further testing to confirm or rule out a hearing loss. Thank you, Steve.

Steve: Oh, thank you. I'm not sure you underscored it, but one of the strategies that I've always found to be helpful – because parents are really passionate about making sure their children do well in school and in future life – is the link between hearing loss and learning, and I know that there are some good resources that you've mentioned about that.

Alejandra: Absolutely. Yes, because when parents understand that hearing it's needed in order for language development and undiagnosed hearing loss has a negative impact on language development, and language is the bedrock of education. Yeah, thank you for bringing that up, Steve. Very important points for parents to understand.

Steve: I think we have time for one or two more questions, and I know you're doing this in Spanish. But off the top of your head, are there any suggested sites that are best for parents for whom Spanish is their only language?

Alejandra: Thank you, yes. We actually put together a whole page of resources with links in Spanish. Please be sure to ... We will share those with you. Yes, we have put those resources together for you. Also, as Steve mentioned, we will be redoing this talk in Spanish next week.

Steve: Thank you. And then finally, is there an age that we should start screening children or help parents understand when this all starts?

Alejandra: Thank you, I love this question. It's always a good time to screen, because children will receive ... If a child is born in the US, we have high screening rates in birth hospitals, but some children, unfortunately, are lost to follow-ups. What that means is that the children might not have passed the screening at birth and then we estimate that about 29% of children that did not pass the screening at birth did not make it to services afterwards. In other words, did not receive diagnostic services. Thirty percent of children are lost to follow up.

It's always a good time to screen because we also know that many children may have progressive or late onset hearing losses. Even if they did pass the screening at birth, they might develop a hearing loss. We know that the statistics will double by the time the child enters the school system. Fortunately, the tools that we use, such as or otoacoustic emissions, can be used

in little babies. It's always a good time to conduct a hearing screening. Thank you, that's a great question.

Steve: Thank you. OK, Alejandra, can I ask you to scroll back or forward, I guess, to near the end of our slide deck here? I can just close this all out. There we go, right there. I just want to remind people that there is a certificate attached to the evaluation, and next slide, please.

I want to thank you, Alejandra, and Kate for running the show backstage, and especially to all the people that were on today your questions, your attention to the detail, and your caring for the children and families in your programs. Next slide, please.

If you have any questions about the evaluation, about the handouts or any other health, behavior health, and safety question, you can write or a call to health@ecetta.info or that phone number, and all of our materials are on the ECLKC, including previous webinars about hearing screening, fact sheets about hearing screening, and hearing screening during COVID that Alejandra wrote.

All of that is at ECLKC at that website address. I want to thank everyone, especially Alejandra, and we're going to end the webinar.

Alejandra: Thank you, everyone. Thank you, Steve and Kate.